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ABSTRACT

This paper describes the Portage County, Ohio community hospice program, emphasizing the linkages between family life specialists, health professionals, volunteers, and students. Hospice service is defined as a specialized, home-based program for the management of pain and other symptoms of terminal illness, with the family as the unit of care. The goals of the Ohio program, i.e., home-based care, education, support, and low cost, are discussed, and background information on the program, including its history, organization, staffing patterns, and services, is provided. The role of the family life specialist is described, emphasizing the psychological and social needs of the family. Training and interdisciplinary leadership responsibilities are discussed. The components of the program's 9-week hospice education and training session, including learning objectives focusing on the hospice concept, death and dying, roles of hospice members, and community resources, are discussed. An outline of the training program by weeks is given in Table 1. The paper concludes with comments and short case vignettes to illustrate the value and unique features of hospice care to the terminally ill and their families. (BL)

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LINKING FAMILY LIFE AND HEALTH PROFESSIONALS, VOLUNTEERS, AND FAMILY LIFE STUDENTS IN A COMMUNITY HOSPICE PROGRAM

Paper presented

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Linking Family Life and Health Professionals, Volunteers

and

Family Life Students in a Community Hospice Program

The purpose of this paper will be
1) to explain the linkages of the family life educator with a community hospice program,
2) to examine the components of hospice education and training sessions developed by health and family life educators,
3) to explain the roles of the family life educator and the family life senior practicum student as members of the interdisciplinary hospice team in counseling and educator roles.

What is hospice service? It is a specialized program for the management of pain and other symptoms associated with terminal illness. The family is the unit of care which is mainly centered in the home. Services are planned to meet the needs of the family members and the needs of the ill person. It is for people of all ages.

The goals of hospice are:
1) to keep the ill family member at home as long as possible
2) to support the family as the unit of care
3) to educate professionals and lay people on the hospice team and in the community at large
4) to help the family member who is ill and his/her family to live as fully as possible
5) to supplement existing services
6) to keep costs down

Ohio Hospice Organization, statewide, was organized in 1978. Programs are now available in many parts of the state. The first hospice in the United States began operating in New Haven, Connecticut in 1974. Some of the programs in the U.S.A. (numbering 500-700) are free-standing facilities, some are hospital based and some are expanded home care.

In Portage County, Ohio Hospice was formed in 1982 using the Kent Visiting Nurse Association (VNA) and Ravenna Visiting Nurse Association as the nucleus of the care givers. Robinson Memorial Hospital agreed to participate as the in-patient service. The county is divided into west half for Kent VNA and east half for Ravenna VNA for this service. A Portage County Hospice Council was incorporated consisting of 24 trustees elected from an original organizing committee of professionals and volunteers. The family life educator is a charter member of the council. This Council collects and disperses funds to the Visiting Nurse Associations and guides the overall program. Every attempt was made not to duplicate any services already available in the county.

Public relations, fund raising, finance, and education committees form the Council committee structure. The Council meets monthly and has hired a coordinator of volunteers. The education committee conducts

periodic training sessions for volunteers and professionals who wish to be a part of a hospice team. This interdisciplinary team of professionals is under the direction of a physician.

Team members may include registered nurses, family life specialists, physical, occupational and speech therapists, clergy, social workers, lawyers, pharmacists, volunteers and others. The volunteers, who are carefully selected and trained, provide support service such as transportation, companionship, recreation and respite for the family caregiver.

Services must be available on a seven day per week, twenty-four hour basis. Staff fatigue and burnout are 'occupational risks.' Thus, staff support and communication one-to-one and in groups is necessary to meet the emotional needs of the hospice team.

Persons who are terminally ill should be accepted for hospice services based on health care needs, not ability to pay. Financial support from community and private donations is crucial.

Role of Family Life Specialist

What is the role of the family life specialist? Sometimes the psychological and social problems that confront terminally ill persons and their families are often more distressing than the disease. The family is going through a time of multiple acute stress and grief, and needs care, as does the ill member. One study indicates that the family member carrying the primary burden of care suffers, more anxiety, depression and social malfunction than the terminally ill member.[2]

Family life counselors have a very important role in helping the family members deal with their anxiety and depression so that they in turn can be supportive of the ill person. The family life specialist needs to take an overview of the family situation. Are there long term family conflicts? Is the ill person the sole economic support? What members are available for daily care giving?

Family members often neglect their own needs. Over time, this may lead to neglect of the ill member, anxiety and finally, resentment. The counselor can help prevent this. It is important for families to be able to give aid and support. Studies show those involved in care are less prone to guilt than those not involved.[3]

Help is needed with adjustment to the idea of life without the ill member of the family, even while that person is still alive. After death, bereavement counseling for the family by a family life counselor is an important part of the hospice concept. The grieving are more susceptible to psychological and physical illness. The interdisciplinary hospice team can give immeasurable support during this time.

Family life specialists are also an important part of the training of volunteers as companions and respite care givers throughout this program. Team training is required on a 6-12 week basis depending on how a particular hospice program is conducted.

Family life counselors are invaluable in giving staff support to individuals or during group sessions, formed to deal with staff burnout and specific concerns.

Family life professionals should have a voice as the state health certification agencies debate hospice certification across the country. Regulations must provide quality of care while at the same time allowing variations in organizations according to special family and community needs.

The family life educator is an effective leader for the hospice team approach because of the interdisciplinary nature of his/her education and the need in hospice programs to extend care to the entire family.

Components of Hospice Education and Training Sessions

The education committee of Portage County Hospice Council organized a six week training session for everyone plus an extra two weeks additional training for volunteers. All council members, Robinson Memorial Hospital staff nurses, hospice physicians and volunteers participated in the training. All speakers gave their presentations without reimbursement for their time and mileage. We believe this represented the spirit of giving and sharing that characterizes the hospice movement.

Objectives for participants in training program include the following.

1) to gain knowledge of the hospice concept
2) to learn about dying, death, and bereavement
3) to understand the roles and functions of hospice team members and their work with the family and the ill member
4) to gain information concerning available community resources that may be called upon for help.

For outline of the Portage County Hospice training program see Table I.

Hospice As A Service Opportunity and Practicum Experience for Senior Students

Family life educators need only to examine the hospice philosophy and competencies to see that their professional skills meet the needs of this new field. They can be the initiator of the development of hospice, concentrating on what is needed for family and patient. Many also possess interpersonal relationship and management skills needed to administer a hospice. Other family life counselor roles include that of patient-care coordinator, director of bereavement help, the family worker on the team, special consultant to the program, hospice director of volunteers, hospice volunteer, corrdinator of education programs, and staff support counselor.

Senior students interested in hospice care could choose any of those working in the above roles as a possible field experience or practicum supervisor. The experience of the past year in Portage County Hospice

TABLE I

Portage County Hospice Council Training Program

Week one: 7:00-9:00 P.M.	The Philosophy of Hospice Speaker: Coordinator of Office of Geriatric Medicine and Gerontology Northeast Ohio Universities College of Medicine Discussion
Week two:	Guidelines for Care of the Terminally Ill Speaker: Director of Hospice Services in another Ohio Community Discussion
Week three:	Caring for the Needs of Family Members Speaker: Family Life Educator Discussion
Week four:	Death, Dying and Bereavement Speakers: Counselors (a mental health and a religious counselor) Discussion
Week five:	The Legal Aspects of Hospice Speaker: Attorney (Includes liability of volunteers and professionals as well as guardianship and wills) Discussion
Week six:	Community Services Speaker: Director Information and Referral Services Discussion
Additional sessions for volunteers:	
Week seven:	Activities of Daily Living (How to assist) Speaker: Director Home Health Aide Services Discussion
Week eight:	Communication Skills Speaker: Professor Family Counseling Discussion
For all:	
Week nine:	Party for all participants in training sessions. Development of hospice teams Evaluation of sessions.

with student practicums would indicate the following: 1) Students should begin with the education program required of all volunteers. 2) For later possibility of later employment, the student should work part of the time with those in the usually paid positions of hospice administrator or coordinator of patient care, volunteers, education or bereavement. 3) A university practicum supervisor is also needed. Hospice care giving is a sensitive area of family concern and students need guidance especially early in their practicum program. 4) The student should also take part in the staff counseling support sessions.

I would like to tell you about a hospice patient. I will call her Lucille. Attractive and gifted, she looked forward to graduating from medical school and embarking on a career as a family practise physician. A few months before her thirtieth birthday she was diagnosed as having terminal cancer. At the hospital she was certainly not the ideal patient. She was angry. She alienated the members of the hospital staff. Fellow patients disliked her because of her tempermental outbursts. If it had not been for the hospice program, she would likely have become increasingly isolated.

Who wouldn't have been angry in her place? The goals of hospice were simply to make sure she suffered as little pain as possible, and to help her deal with her anger. Eventually, both aims were achieved. Hospice team members visited Lucille daily, treating her without pity, but with friendly openness. Letters were written to friends, telephone calls were made to relatives not living nearby. Family members came and went at all hours-not needing to abide by rigid hospital visiting hours. Her sister brought in meals and ate with her. Children that she had worked with in the community were encouraged by the social service worker to have a brief party in her room. Soon her disease was under some control, the family had worked out a plan of care with the hospice team, and Lucille went home. When her husband was at work, Lucille's mother and sister took over primary care. Her sister came on the days she did not have university classes. A volunteer from hospice team came in for half a day on Tuesday, Thursday, and Friday to provide respite care for the family. Her husband spent Saturday and Sunday as her caregiver. At a birthday party held four weeks after her return home, Lucille her anger gone, lifted her glass in salute to her family and friends - "Somehow you have given me the gift of life during this illness. I salute you. I love you." Two days later she died peacefully at home, surrounded by family, her hospice nurse and volunteer friend.

Hospice gives hope in a time of no hope. Families have a chance to to reveal their love and to come to peace and joy in their relationships. Hospice care often prolongs both the length and quality of life by giving the patient the best medical attention and by counteracting distressing symptoms. Distress can kill just as effectively as disease. Pain relief given before pain is severe allows the patient to be aware and to go on living.

One of the unique features of hospice is that the focus of care is on the patient and the family, not on the patient alone. Families have a lot of questions. One member of a newly formed hospice team turned to

a patient's wife after a patient's acute episode and asked, "How are you?" The woman broke into tears and said, "That's the first time anyone has asked how I am."

One man told his hospice family life volunteer that he used to be afraid of dying. "Now, he said, I'm not afraid and I can go on living for the time I have left." That is what hospice is all about - living each day to its fullest.

Health professionals have often been leaders in the hospice movement. Because of their unique qualifications, family life professionals have an important role to play in linking together the interdisciplinary team, including student practicum volunteers, in the family-centered hospice concept of care.

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